

Key facts about living kidney donation

Swiss Living Kidney Donors booklet

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Introduction

Living kidney donation has become increasingly gained acceptance in recent years. While even as late as the mid-1990s few live donations were performed, this form of treatment has now become a routine procedure in many transplant centres. In 2003, for the first time, the number of transplants from live donors in Switzerland even exceeded the number of transplants of organs from deceased donors. A similar trend is emerging in many other countries. This booklet provides information about the risks and benefits of living kidney donation.

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Foreword

The centuries-old dream of mankind of replacing a defective body party became a reality exactly 50 years ago, when the transplant of a kidney from a living donor ensured the survival of the patient concerned. Thanks to modern intensive care medicine it subsequently became possible to remove and transplant organs from deceased donors. In fact, donation from deceased individuals was the commonest source of kidneys used in transplantation up until the beginning of the 1990s.

However, the growing number of kidney transplants from live donors performed in the 1980s has shown that this procedure is a very effective therapeutic option. Experience has also shown that the risk for donors is acceptable. At the same time, the outcome after a live kidney transplantation was found to be much better than after a dead donation. These positive results and the growing shortage of organs have resulted in a huge increase in live kidney transplants: In 2002, for the first time, the number of live donors in Switzerland exceeded the number of dead donors.

The crucial factor in a live kidney transplantation is naturally the donor. Accordingly, the Swiss Organ Living-Donor Health Registry was created in 1993 – the first living donor registry in the world. The registry has three main objectives:

1. Analyse the risks after live donation,
2. Identify at an early stage any problems after donation and
3. Inform the donor and his/her doctor if any such problems are identified.

The information that we have hitherto been able to pass on to potential future donors is based on experience acquired by patients who have lost a kidney (for example as a result of an accident) and our own experience with living donors. Thanks to the Swiss Organ Living-Donor Health Registry we now have sufficient data for a 10-year analysis of living donors. Professor Gilbert Thiel, the originator and person in charge of the Living-Donor Health Registry, analysed the data from the register and has presented the findings in this booklet. This analysis has enabled us to quantify the precise risks involved. We can differentiate between the risks associated with the operation and the immediate post-operative phase

and the so-called long-term risks resulting from the fact that the donor only has one kidney. While we have simplified this data and presented it in summary form for ease of comprehension, the actual figures from the Swiss Organ Living-Donor Health Registry can be retrieved from the website of the Swiss Organ Living-Donor Association for Liver and Kidney Donors: www.lebensspende.ch

If you yourself are thinking about donating a kidney, but would first like to talk this over with someone who has already been through the process, the President of the Living-Donor Association would be delighted to get in touch with you. She can best be reached via the following e-mail address: er.birbaum@bluewin.ch

In addition to important details about the risks, this booklet also contains other valuable information on the following topics: suitability as a living donor, the possible combinations of living donor to recipient, the various techniques of kidney removal, the possible pain involved, the hospital stay, the financial consequences and, last but not least, possible psychological problems. The relevant sections can be located via the table of contents.

This booklet is designed to serve as a source of information for individuals who are interested in the subject or who are thinking about donating a kidney.

Although we have incorporated the experience obtained with the first edition of the living donor booklet in this second edition, there is undoubtedly room for further improvement. We would therefore be pleased to receive any suggestions so that we can further improve this information for the benefit of potential living donors.

Professor Jürg Steiger MD

A handwritten signature in black ink, reading "J. Steiger". The signature is written in a cursive, flowing style with a large initial "J".

Is living kidney donation necessary?

Dialysis and transplantation are the options currently available for replacing a kidney. While both procedures will preserve the life of a patient with serious renal disease, the dialysis treatment restricts the everyday life of the patient and thus leads to a poorer quality of life. Because of the serious shortage of organs from deceased donors, many patients have to wait years for a transplant. Living kidney donation can shorten this waiting period and allow more patients to receive a kidney transplant. An increasingly important point to bear in mind in relation to the healthcare system is the fact that dialysis treatment is many times more expensive than transplantation.

So why is live donation increasingly gaining acceptance?

There are two main reasons: Firstly, almost all countries are experiencing a severe shortage of organs from deceased donors. Secondly, the outcome after a living kidney donation is much better than after transplantation from a deceased donor. Moreover, the substantial progress made in the associated anaesthetic and surgical techniques has minimized the risk for a live donor. The benefits of a living kidney donation generally outweigh the risks.

What are the advantages of living kidney donation?

Organs from living kidney donors function longer, on average, than organs from deceased donors. This advantage applies not only to transplantations between relatives (e.g. sibling to sibling, or parent to child) but also to transplants between donors and recipients who are not blood relatives (e.g. husband to wife or friend to friend). The better results for live kidney transplantation can partly be explained by the shorter time during which the organ is not supplied with blood and partly by the transplantation of “healthier” and, on average, younger kidneys. If a live kidney transplant is planned in good time for a patient with a diseased kidney, dialysis treatment can even be avoided altogether. When the patient then ultimately develops full-blown renal failure, transplantation can be performed immediately (“pre-emptive transplantation”). This avoids the situation of partial or complete loss of ability to work. Since the patient remains in work, his self-esteem is raised and the overall costs are reduced. Another advantage of a **planned** living kidney donation is that it can take place while the recipient is still in good general health. In Switzerland, the average waiting time for a cadaver kidney is

1–4 years depending on the recipient's blood group. Arranging a possible living kidney donation also makes sense therefore for patients who are already receiving dialysis and on the cadaver kidney waiting list, as this can shorten the waiting time.

What factors make me a suitable living kidney donor?

In principle, any adult with two healthy kidneys can donate a kidney. The traditional view that only healthy individuals can donate a kidney is not correct. People with certain illnesses can also make a living kidney donation (see below). The most important factor is blood group compatibility, although the blood group does not always have to be exactly the same. The following combinations are compatible in terms of blood groups:

Donor's blood group	Recipient's blood group
O	O, A, B, AB
A	A and AB
B	B and AB
AB	AB

Since tissue compatibility is less important these days, any adult can, in principle, be considered for a donation provided the blood groups are compatible. Of course the medical history of the potential donor will need to be taken into account and a full medical check-up performed.

Can I donate a kidney to my child?

Provided the blood group matches and you are healthy, this is a very natural option. Many parents are only too willing to donate a kidney to their child, and this also corresponds to the natural progression of the generations.

Can I donate a kidney to one of my parents?

This combination for a living kidney donation is less common, since the children are usually still relatively young and their life plans are often in their early stages or are not yet completed (family planning, partners, etc.). Nevertheless, many transplantation centres also transplant live kidneys from an adult son or daughter to a parent. Particularly careful clarification and explanation is important in such cases in order to identify and discuss any misconceptions or false expectations.

Is donation between relatives better than between non-related donors and recipients?

Transplantation between siblings, who have the advantage of complete tissue compatibility, is the ideal situation since this offers the best chances for transplant survival, rejection almost never occurs and fewer drugs are needed to combat rejection. A half-match (i.e. half of the tissue features match), which can often exist between parents and children or between siblings, is still promising, though the benefit is much less. If there is no half-match for the tissue factors between related donors and recipients, the outcome is the same as for a non-related living kidney donation. However, the outcome for living kidney transplants overall is better than for transplants involving organs from deceased donors.

Can grandparents also donate kidneys?

Live donation by grandparents is particularly advantageous for children and young adults. This is because some 50% of transplanted kidneys are no longer functional after 20 years, which means that a child or adolescent will require more than one transplant in his or her life. If the first transplant comes from a grandparent, a second transplantation is then possible at a later stage (e.g. from a parent, sibling or other relatives).

Is donation possible between life partners and close friends?

In this combination, both the donor and recipient profit from the kidney transplant in a special way. The donor contributes to the recovery of the sick partner or friend, thereby improving the latter's quality of life. This, in turn, has a positive effect on the relationship. As a result, the combination is particularly favourable.



Kidney donor Claudia Maurer-Wolf, 56, Feldenkrais teacher, and kidney recipient Thomas Maurer-Wolf, 56, toxicologist, Rodersdorf, Solothurn

Thomas Maurer My kidneys were always the weak point of my health and I suffered from nephritis during my childhood. Shortly before Christmas 2003 I developed acute renal insufficiency due to sclerosis and residual scarring of unknown origin. According to the doctors, however, this was not related to the chronic progression of the earlier condition. The symptoms were itching, diarrhoea and, finally, fluid in the legs with an associated rapid weight gain.

Suspected renal failure was the obvious diagnosis, particularly since the results of my blood tests two years previously showed a sudden deterioration. When my doctor immediately referred me to hospital for further investigation, I knew what this meant and what the next steps would involve: dialysis or a kidney transplant. Although drug treatment helped stabilize my condition, no one could predict how long this measure would suffice. The kidney

specialist explained to me that a kidney donation would be the ideal solution, and the sooner the better.



Claudia Maurer In spite of my husband's medical history we had never actually discussed the possibility of kidney donation. When I went with him to see the kidney specialist in Basel University Hospital, I learned that the earliest possible transplantation of a donor kidney could help avoid any further deterioration of his kidney function and the resulting need for dialysis.

I was determined to donate one of my kidneys if the initial medical investigations showed me to be a suitable donor. Of course, I knew that my blood group was a suitable match for my husband, and then the other checks also proved positive - from the general state of physical and psychological health, renal function, blood tests, immune system and many other factors right through to gynaecological aspects.

Following the comprehensive initial discussion with the kidney specialist and psychologist, I was given the go-ahead for early kidney donation and transplant.

We have since met several couples who are in the same situation. Apparently, living donation between life partners is possible in many cases, and such donations are even more common than transplantations of kidneys from deceased donors.

Thomas Maurer Thanks to my wife I received the best treatment without delay: The initial consultation was in mid-January, at the start of April we made the decision to proceed with the live donation and I received the healthy kidney at the start of May. In other words, the investigations took around two months to complete and 6–8 weeks later everything was ready for the operation.

Since my condition had not deteriorated during this relatively short period, I was in the ideal position for a textbook transplantation and a quick recovery. Fortunately, the only complication was urinary retention after the removal of the catheter. I spent eleven days in hospital compared to my wife's stay of

seven days. My blood levels had improved by half just one day after the operation and had almost returned to normal by the time I left hospital. The first check biopsy after three months showed no signs of rejection of the new kidney.

If the second biopsy taken at six months after the procedure produces the same result, I can look forward to a long life for my new kidney. Of course, I shall have to take immunosuppressants – drugs to combat rejection – every day for the rest of my life, although the dosage and number of tablets will decline in the future.

Claudia Maurer We were given a complete and clear explanation in a calm, open atmosphere and felt well looked after. The hospital staff were always prepared to listen and take time to address our questions and concerns. The transplantation proceeded uneventfully, although the surgeons discovered that my left kidney was supplied by three arteries and my right kidney by two arteries instead of just the one, which meant that the open removal technique was required. Both operations lasted around two hours, which is only possible for the recipient if, as is usual, the diseased kidney does not need to

be removed. All that's left is the operation scar – albeit a fairly long one because of the flank incision. Initially, restricted movement immediately after the operation was a problem for me because I had always been perfectly healthy until then.

After seven weeks I was able to resume my job, which involves working physically with people. My husband, who commutes to Berne three times a week, returned to full-time work just three months after the operation. Since then we have resumed our normal lives and have even started taking up sporting activities again.

Can I donate a kidney to an unknown recipient?

Donation by an individual to an unknown recipient is known as a “non-targeted” live donation, as opposed to a “targeted donation”, where the donor gives his organ for the benefit of a particular person. If the donor does this for purely selfless reasons, this is known as an “altruistic donation”. Such a donation was officially recorded in Switzerland for the first time in 2003. This was agreed in advance with the Swiss Federal Office of Public Health and with SwissTransplant. A donation for an unknown individual is therefore possible in principle, but is subject to the need for complete anonymity. An altruistic donor is carefully investigated in respect of his motivation and requires an in-depth psychological assessment.

Can I donate a kidney even if my blood pressure is too high?

This question was extensively discussed around ten years ago and answered positively by experts. Such a donation is subject to strict rules however. Candidates for a kidney donation who have pre-existing high blood pressure may be accepted only if the blood pressure can be maintained at a normal level with a maximum of two drugs and if no negative effects on the heart (thickening of the heart muscle), eyes or kidneys (protein excretion) are detected or if any such effects have responded to blood pressure treatment. The introduction of this policy has meant that around 15% of donors currently have a history of elevated blood pressure. How has this policy worked out in practice? Essentially fine, although donors who had been experiencing blood pressure problems before their kidney was removed will continue to require more antihypertensive medication, even years later, than donors who only developed a high blood pressure after the removal of a kidney (nephrectomy). Consequently, anyone wishing to donate a kidney despite suffering from pre-existing high blood pressure must take account of this need to take several antihypertensive drugs in the future.

Can I die as a result of donating a kidney?

The worst complication associated with a kidney donation is the death of the donor during, or after, the operation. Although a nephrectomy is a very safe procedure, there is nevertheless a risk that the patient could die as a result of this operation. According to the best estimates, this risk is approximately 0.03%, which is equivalent to **one** fatality per 3000 kidney donors. A recent analysis of 10,828 nephrectomies in the USA performed between 1999 and 2001 confirmed this estimate. Although no donor in Switzerland has died to date in connection with a kidney removal, one should assume that a comparable risk still applies.

What's the effect on my life expectancy from donating a kidney?

The removal of a kidney does not have any adverse effect on life expectancy. In fact, according to the statistics, kidney donors lead longer and better-quality lives than their non-kidney-donating counterparts. This improved life expectancy is probably connected with the fact that those individuals who are approved for a kidney donation must be in a reasonable state of health. The satisfaction of donors is also higher after the donation compared to the normal population.

How much kidney function will I have after donating a kidney?

Following the removal of a kidney, the renal function falls to around half the normal level, but only in the short term because the remaining kidney is capable of assuming some of the tasks of the removed kidney. In the long term, the level of renal function is approx. 70% (compared to the function before the donation). This renal function is perfectly adequate for leading a normal life. Renal function declines with increasing age. Comparative investigations between kidney donors and non-donors have shown that the kidney donation does not lead to a faster loss of function during the course of the ageing process.

Am I at an increased risk of suffering from renal failure myself?

The risk of a kidney donor suffering from a serious restriction of renal function him- or herself is between 0.04% and 0.3% (1 kidney donor in 2500 donors to 1 kidney donor in 300 donors). Compared to the average population, for whom the probability is approx. 0.03% (1 in 3000), the risk is slightly higher, though still very low. The principal causes of renal failure in former kidney donors are damage to the kidneys due to high blood pressure and renal disorders that directly affect the kidneys (e.g. the condition known as glomerulonephritis). It is worth noting that, of the 631 living donors in Switzerland recorded in the living-donor register, none has required long-term dialysis to date.

The doctors in your transplant centre can advise you and explain whether you are at an increased risk of suffering from a renal disorder. In order to avoid damage to the remaining kidney as a result of high blood pressure, it is absolutely vital that all future kidney donors should have their blood pressure under control. This is the best insurance for the remaining kidney.

Are there differing techniques of kidney removal?

A distinction is made between the open technique and what is termed the “key-hole” technique (i.e. involving a laparoscopy or retroperitoneoscopy).

Open removal technique

The open removal technique has become the standard procedure worldwide for living kidney removal. In this procedure the kidney is removed through an approx. 15–20 cm skin incision following the arch of the ribs. The disadvantage of this surgical technique is the long scar produced as a result of the operation. This technique is primarily used in donors whose kidney is supplied by several blood vessels.

Laparoscopic technique

Given the advantages of the endoscopic surgical technique, commonly known as the keyhole technique, transplantation centres worldwide are increasingly changing over to this method, which has become familiar and proved successful particularly in the context of gall bladder removal. In laparoscopic nephrectomy, the abdominal cavity is opened under camera control and the organ is removed with special instruments. Specifically, a total of four small incisions are made in the abdominal wall through which a camera and the operating instruments are then inserted into the abdominal cavity. The kidney is then exposed and finally removed through an approx. 10 cm skin incision.

Retroperitoneoscopic technique

Since the kidneys are located in the retroperitoneal space (space behind the abdominal cavity), an alternative technique involves retroperitoneoscopic removal. Like the laparoscopic technique, this is an endoscopic procedure (keyhole technique). But in contrast with laparoscopy, the kidney is approached from the side (i.e. behind the abdominal space) rather than via the abdominal cavity. In fact, this cavity does not actually need to be opened in this technique. The kidney is again exposed under camera control using special operating instruments and finally removed through an approx. 10 cm skin incision. This technique can prove advantageous for obese donors or those who have undergone previous abdominal surgery.

Regardless of the surgical technique, the kidney is preferably removed in the manner that will pose the least risk to the donor. The number of renal blood vessels plays an important role in this decision (as a rule the fewer the number of vessels, the simpler the removal). Unless otherwise indicated, the left kidney is removed as this is simpler to implant in the recipient because it has a longer renal vein. In approx. 30–40% of cases the right kidney is removed because of special circumstances (usually complex vessel configurations).



Kidney recipient Tina Pargaetzi Vogel, 49, anaesthetic nurse, Bottmingen, Basel-Landschaft

Even as a small child I had kidney problems, although I never knew the precise cause. My situation became life-threatening towards the end of last year when oxalic acid stones blocked my kidneys. Oxalic acids occur in natural foods such as rhubarb or Swiss chard. At first I “only” had oedema in my legs, which I treated by dietary measures. As time went on, however, a lot of fluid accumulated in my body. I became listless, needed plenty of sleep, felt exhausted and had difficulty in getting rid of the fluid. Friends of mine, a doctor couple, spoke to me about it one evening. We talked about my problem, and they made an appointment for me to come and see them in their practice the next morning. The laboratory tests revealed seriously pathological kidney values, and

the diagnosis was both obvious and alarming: terminal renal failure. They immediately referred me to Basel University Hospital, and I was put on dialysis the very next day! That was on 15 December 2003. I had to undergo dialysis three times a week. Then in March this year my urine production stopped completely. On 22 June I received a living donor kidney. This all happened incredibly quickly when you think that dialysis patients normally have to wait for two to four years – depending on the blood group – for a suitable kidney.

I was extremely fortunate because one of the witnesses to my marriage, and also a professional colleague, who was twelve years younger than me, spontaneously offered to donate one of her

kidneys. I asked her to think carefully about this step, but she stuck to her decision and was confident that her kidney would be a suitable match from the medical standpoint. And she was proved right: After the positive psychological investigations, the cross-match revealed that her kidney was highly compatible with my own body. And so I received the greatest gift that a person can give to a close friend: the sacrifice of a part of the body in order to save the life of the other person.

I can hardly begin to describe the emotional feelings that this triggered in me. Initially, I found it difficult to cope emotionally particularly in the first few days after the transplantation and talked about this with the hospital psychologist. I have since learned to gratefully accept this almost unbelievable gift from my friend, and I never have the feeling of carrying a foreign organ in my body. It's now my own kidney – although hardly a day passes without my thinking about her. But this immense gratitude should not be allowed to lead to dependency.

But I am also hugely indebted to everyone who looked after me and saw to my needs in the teaching hospital with such professional competence and

kindness both before, during and after the operation – and continue to do so even now. And I don't think that I have received any special privileges simply because I happened to be a professional colleague – apart from the fact that my donor and I were able to choose the surgeons and the anaesthetist.

In retrospect – even though just seven weeks have elapsed since the transplant – I can say that the live donation not only kept me alive, but has also given me a feeling of being healthy that I had never experienced with my diseased kidney. I now have a new, more intense feeling of being alive.

Will I suffer pain after donating a kidney?

Of the individuals recorded in the SOL-DHR (**S**wiss **O**rgan **L**iving-**D**onor **H**ealth **R**egistry), 337 kidney donors to date stated, at the time of hospital discharge, that they had suffered pain during their hospital stay. The intensity of the pain reported by the donors varied greatly. In most cases, the pain was described as being “slight to moderate”. Just under 10%, however, reported the procedure as being fairly painful, while one in 40 donors even described the kidney donation as being “very painful”.

The figures for pain only differed slightly for the various removal techniques, and neither laparoscopy nor retroperitoneoscopy provided any major improvement in this regard. The method of pain control and the adaptation of the drugs to the intensity of pain probably play a more important role than the actual removal technique.

Donors who are particularly sensitive to pain are advised, on the evening preceding the operation, to draw the attention of the anaesthetist, the relevant surgeon and the nursing staff to their fear of pain and the desire for effective pain management. This is especially justified for completely fit and healthy individuals who voluntarily accept the burden of an operation for the benefit of others.

If the pain management proves inadequate during your hospital stay, please inform the relevant doctors and nursing staff immediately so that the medication can be adjusted accordingly.

How long will I have to stay in hospital after a kidney donation?

A hospital stay of 7–14 days can be expected. Individual factors will primarily determine when a personal recovery is complete.

What possible problems can I expect during and immediately after a kidney removal?

The early complications during the donation and post-operatively have been systematically recorded in the Swiss Organ Living-Donor Health Registry since 1998 for 393 kidney donors. The following **“important early complications”**

have occurred in the 393 kidney donors to date, arranged in decreasing order of frequency:

- 1) depression during the first few days following the kidney donation (1.5%)
- 2) severe pain (1.5%)
- 3) pneumonia (1.2%)
- 4) injury to a major lymphatic vessel with leakage of lymphatic fluid into the operation area (<1%)
- 5) bleeding requiring a blood transfusion (<1%)
- 6) bruising (<1%)
- 7) air between the chest wall and the lung (pneumothorax) (<1%)
- 8) intestinal problems (<1%)
- 9) broken rib (<1%)
- 10) pyelitis in the remaining kidney (<1%)
- 11) epididymitis (<1%)
- 12) pulmonary embolism (<1%)
- 13) heart attack (<1%)
- 14) temporary paralysis of the arm (caused by the patient's position during the operation) (<1%)
- 15) state of confusion lasting for several days (<1%)
- 16) acute serious conflict in the relationship between the donor and recipient (<1%)

What longer-lasting consequences of the operation should I be prepared for?

There are three main consequences: 1) scar problems, 2) incisional hernias/weakness of the abdominal wall and 3) pain not directly in the scar area.

Scar problems

Scar problems are reported by 12.9% of kidney donors one year after donation. After five years the figure is still 8.2%. The symptoms reported one year after donation are dominated, at 8%, by painful sensations such as “dragging pain”, “itching pain”, “tenderness”, etc. Less commonly reported symptoms are loss of feeling (2.2%) or painless itching (0.7%). After five years, painful sensations in the scar area are still the predominant problem.

Incisional hernias/weakness of the abdominal wall

An incisional hernia was reported to the living-donor registry for just 1 kidney donor. Three other donors (0.8%) were reported as having an abdominal bulge that was outwardly similar to an incisional hernia, but diagnosed as abdominal wall relaxation (weakness of the abdominal wall).

Pain (not in the area of the scar)

Pain is reported one year after kidney donation by 16.4% of the donors. The commonest type (10.0%) is **back pain** in the area of the lumbar spine. Most of these patients, however, had been aware of such pain even before the kidney donation. Only 3 donors (0.4%) reported that the pre-existing back pain had intensified since the donation. The connection with the kidney donation is questionable, however, since 84 of the 631 registered kidney donors (13.3%) had already reported periodic or chronic back problems before the donation – i.e. a higher percentage than one year after donation. In rare cases (0.7%), dragging **kidney pain** in the area of the nephrectomy is described, while **abdominal pain** is equally rare (0.7%).

When will I be able to return to work after the donation?

Because of the time needed for the wounds to heal, a recovery phase of at least four weeks from the day of the operation is recommended. Depending on the particular job however (e.g. heavy physical labour), the return to work may be postponed until 6–8 weeks after the operation.

After the donation, when will I feel as fit as I was before the donation?

Employed donors generally return to work 3–4 weeks after donation, and self-employed individuals and housewives usually earlier. This doesn't mean, however, that they then feel as fit as they were before the donation. 223 donors replied in writing to the question asking how long it took before they felt just as fit as they were before the operation. On average it took three months to achieve their former fitness, although individual periods varied greatly.

If your recovery is delayed after a kidney donation for whatever reason and you no longer feel really fit, please report this fact to your transplantation centre **and**

the Swiss Organ Living-Donor Health Registry. It is very important to us that you should feel completely well again.

Who pays for the costs of a living kidney donation?

The recipient's health insurance fund, which saves money in the long term as a result. This is confirmed by the calculations: After a successful transplantation, the cost of dialysis treatment no longer applies and, depending on the type of dialysis, this can amount to between 45,000 and 80,000 Swiss francs a year. The follow-up costs for a transplant, by contrast, are much lower. To this can be added another advantage for society: Transplanted patients can frequently return to work after a certain period.

Who reimburses the donor for loss of earnings?

The recipient's health insurance fund. At least 80% of the resulting loss of earnings is reimbursed. Unfortunately, not all health insurers are currently prepared to pay for domestic help for donating mothers/fathers with children. In such cases, the individuals concerned have had to ask relatives, friends or neighbours to help out.

Is insurance cover provided for the donor?

The recipient's health insurance fund is responsible for covering the costs of all problems arising after a donation, provided the fund is a member of the SVK (*Schweizerischer Verband für Gemeinschaftsaufgaben der Krankenversicherer* = Swiss association for joint tasks of health insurers) and the link between the problem and the donation is accepted. In other words, if complications occur, the donor is insured by the recipient's fund for the necessary medical interventions and treatment. While there is no standard ruling concerning any additional life insurance, certain transplantation centres also take out life insurance for the donor in addition to the insurance cover mentioned above. This covers death and invalidity and is valid for a year. Once the new Swiss Transplantation Act has come into force, the tiresome problem of insurance will largely be resolved. At least that is the aim of the legislation, although the final version of the law still needs to be passed and enacted.



Kidney donor Peter Schär, 57, project manager, Administrative Board of Emmental Regional Hospital, Langnau, Berne, and kidney recipient Beat Schär, 61, anaesthetist, Trimbach, Solothurn

Beat Schär It was during my childhood that my kidney was found to be damaged (glomerulonephritis), although it continued to function as normal. A cystic kidney was then diagnosed eight years ago, and it was thought that a replacement would be needed – either dialysis or a transplant – after my retirement. Unfortunately my renal function deteriorated rapidly, forcing a decision to be made two years ago.

We had discussed the problem in the family, and my wife had declared her willingness to act as a kidney donor. But when the matter came to a head, the kidney specialist asked me whether I had any siblings, as the quality and compatibility of the transplant are better between blood relatives.

I explained my situation to my brother and sister. They were absolutely amazed because I showed no outward signs of the illness, which only manifested itself in the laboratory test results. Having discussed the matter together and after a briefing session with the kidney specialist, my brother and sister talked with their respective families. Both had agreed to undergo a living donation, and the investigations produced outstanding results. In the end, it was decided that my brother would be the donor.

Despite a strict diet and intensive medication, my laboratory test results deteriorated. I had to undergo dialysis for two months, but was able to continue my work as an anaesthetist until short-

ly before the procedure. Although I felt healthy, my family noticed that I was becoming withdrawn, focusing all my interest and energy on my work.

Peter Schär In the spring of 2002 I received a letter from my brother explaining his predicament. Since I was jointly responsible for a hospital with a nephrology department, I knew what renal failure meant. I immediately thought: “Now perhaps I’ll become a kidney donor.”

My wife, my daughters and I discussed the situation, weighed up the risks for ourselves and the benefit for my brother. In Basel I was told what to expect and was assured that in no way could my brother pressurize me into making a donation. I was told that I had to decide of my own free will and that convincing reasons could always be given for any negative decision. With this assurance and being completely aware of all the implications, I imagined what my subsequent life and that of my brother would be like if I decided for and against an organ donation. In the end I decided in favour of the donation. The future burden of not having helped my brother would have been greater than

the anxiety about the risks involved or any failure.

The course of the illness dictated the need for an operation in 2003. I underwent investigations from April until the operation at the start of September. Except in the angiogram, no complicating factors were discovered - nor did any complications arise during or after the organ removal. I even remained largely pain-free, probably thanks to the use of the laparoscopic technique, which also involves minimal residual scarring. Nor have I experienced any feelings of anxiety or depression. I remained in hospital for a week, spent a week and a half recuperating at home and then went on holiday. I returned to work four weeks after the procedure.

Today I feel very happy about my decision to donate a kidney, which was made easier by the fact that I had a very long time to prepare myself for the donation. I like hiking, drive a motorbike and feel fit. The doctors specifically warned me about the increased risk associated with motorcycling for my remaining kidney and advised me to give it up. But I’m afraid I’m hooked!

Can the donated kidney fail? If so, what happens then?

After one year approx. 95% of all live kidney transplants are still functioning. Expressing it the other way round, approx. 5% of the transplanted organs lose their function in the first year. The leading causes of early transplant failure are surgical complications in the recipient or serious, untreatable rejections. There is still no test available for predicting whether such serious rejection reactions will occur. It should be borne in mind, however, that serious rejections leading to a loss of the transplant are rare. Otherwise, rejections, particularly during the first six months after transplantation, are just part of everyday transplant life, respond well to treatment and do not lead to transplant loss. It can therefore be concluded that a transplantation attempt is definitely worth risking in view of the good overall chances of success.

Living kidney transplants that have successfully survived the early phase have a good long-term prognosis. While one can never predict exactly how long the transplant will continue to function in the individual recipient, we know from large-scale observation studies that half of all live kidney transplants are still functioning after some 20 years. These are the best results that can be achieved nowadays.

What restrictions will I have to cope with as a donor?

What do I have to watch out for?

There are no restrictions and there's nothing to watch out for! Kidney donors can, and should, lead a completely normal life. They do not have to stick to a diet or restrict the amount they drink. The remaining kidney is well supplied and located in a secure part of the body and perfectly capable of meeting the needs of a long and normal life. If at all, the only advice to bear in mind is to avoid sports and activities involving an increased risk of violence (combat sports, ski-jumping, hang-gliding or similar activities) and thus minimize the extremely rare possibility of damaging the kidney as a result of an accident or violent impact.

Otherwise, the donor only needs to live a healthy modern lifestyle. But rather than acting as a restriction, this actually enriches life. Cardiovascular risk factors (factors that are harmful to our cardiovascular system and the heart) should – where applicable – be reduced, for example by taking adequate exercise and practising sport, eating a balanced diet, striving to maintain a normal weight or

losing weight, lowering elevated blood fat levels (i.e. cholesterol) and giving up smoking.

Most important of all, though, is blood pressure. Ideally, the blood pressure should be 120/80 mmHg. High blood pressure is not something to be taken lightly. The remaining kidney works perfectly well, but it should not be exposed to the possibility of damage due to elevated blood pressure. Quite the opposite: it must be protected against high blood pressure. For this reason, living kidney donors should have their blood pressure checked at regular intervals (at least once a year).

In order to detect any additional burden on the remaining kidney as early as possible, the protein excretion of the kidney must also be checked regularly (every 1 or 2 years). As part of the follow-up regimen of the Swiss Organ Living-Donor Health Registry, you will be invited to an appointment with your doctor or the transplantation centre. If you do not receive your invitation as a result of an oversight, please inform your transplantation centre or the Living-Donor Health Registry directly (page 31).

If you suffer from high blood pressure or if increased protein excretion via your kidney has been detected, or is detected in the future, please be sure to take the antihypertensive drugs prescribed by your doctor. Keeping your blood pressure under control is the best insurance for you and your own kidney!

Can my remaining kidney become damaged?

Yes, but this is largely avoidable. The remaining kidney immediately takes over much of the function of the kidney that has been removed. The resulting increased workload and rise in pressure in the remaining urine-producing organs can, over the years, lead to signs of wear. An early warning sign of this phenomenon is the increased excretion of protein in the urine. This explains why the Swiss Organ Living-Donor Health Registry stipulates that the protein excretion in the urine must be accurately measured every two years. If the figure is above normal, you and your doctor will be informed accordingly in writing by the Registry and corresponding treatment recommended. The damage can be countered by an appropriate drug that also keeps your blood pressure at normal levels. Seven years after donation, 9% of living donors have an excessively high level of protein excretion in the urine (known as albuminuria), and this should be treated as discussed above.

Does the kidney donation lead to high blood pressure (hypertension)?

Seven years after donation, 34% of the donors on the Swiss Organ Living-Donor Health Registry showed elevated blood pressure (hypertension), although high blood pressure had already been measured even before the kidney donation in 15% of cases. In fact, the blood pressure of kidney donors 5–10 years after donation is no different from that of the Swiss population of the same age. A single exception, however, is the group of 65–75 year old kidney donors, in whom a tendency towards elevated blood pressure readings is evident. Results from a comparable study in Sweden likewise show no differences compared to the general population. Overweight donors, on the other hand, are at increased risk of suffering from hypertension, since 40% show an elevated protein excretion in the urine five years after donation, while 70% have an elevated blood pressure seven years after donation. Fortunately, both conditions – the elevated blood pressure and the protein excretion – can also be treated successfully in overweight kidney donors. Overweight individuals who nevertheless wish to donate a kidney must undergo regular medical check-ups and be prepared to take antihypertensive medication, if indicated, for the rest of their life. However, such individuals would probably have to do this sooner or later in any case even without a kidney donation.

Can the donation trigger psychological problems?

Every stage of the donation has its own psychological obstacles that need to be negotiated as far as possible.

Three pieces of advice are worth noting for the phase **before the transplant** in connection with the consent for live donation:

- 1) Anyone who feels under an obligation to donate a kidney to a sibling, life partner, child, etc., but does not actually want to do so, should inform the transplant team accordingly. There is certainly nothing to be ashamed of and no need for lengthy explanations. Possible solutions can be worked out in such cases.
- 2) Organ donation is not an advisable way of patching up a rocky relationship between the donor and recipient. Anyone donating an organ with this hope in mind can subsequently be severely disappointed.

- 3) Anyone wishing to donate a kidney to a sibling or other relative must always discuss this carefully with their life partner before giving their consent. Otherwise, unpleasant conflicts can arise, for instance, a man may wish to donate a kidney to his sister, even though his wife can't stand her sister-in-law and certainly does not wish to see the health of her husband put in jeopardy for the benefit of his sister. A living donation between siblings is a more delicate matter in psychological respects than one between life partners.

New problems emerge during the period **immediately after the operation**: If the donor is put in the same room as the kidney recipient, feelings of anxiety can arise on both sides, particularly if one of the two patients experiences problems. If the donor and recipient are accommodated separately, which is probably the better option, many donors are painfully aware that, for the first time, the centre of attention has suddenly moved away from them. The doctors now visit the kidney recipient several times a day. "That's just as it should be", say the donors concerned, "but they hardly pay any attention to me now and that's not so good."

Depression can occur suddenly and unexpectedly shortly after the donation, even though the transplant has passed off successfully. This unexpected change of mood is comparable with the depression that occurs after a successful childbirth, just when the mother would be expected to feel happy. Fortunately, depression shortly after a donation is a temporary condition that generally lasts for just a few days or, in rare cases, a few weeks. However, depression shortly after donation is not a common problem, having been observed in just six out of 393 donors on the living-donor registry (1.5%).

As time passes, the psychological well-being of donors is generally good. For those donors in whom this does not apply the reasons are usually very obvious: e.g. the loss of the donated kidney or problems in the kidney recipient that the donor had not anticipated – and in the worst-case scenario the death of the recipient. Talking over problems with other living donors can often help. Formed in March 2004, the Swiss Organ Living-Donor Association for Liver and Kidney Donors has set itself the task of organizing self-help groups and meetings with people who have already donated a kidney. Making contact with this association is recommended in any case: www.lebensspende.ch

Do former kidney donors ever regret giving their organ?

In response to the question “If you could decide again whether to donate a kidney, would you proceed with the organ donation?”, 95% replied “Yes” and 5% “No”. The great majority of donors have a very positive attitude to donation and transplantation, even those that have experienced problems.

Do I as a donor have any claim to compensation?

Not in terms of material compensation in the form of money or goods. The sale of organs is banned in Switzerland and that is always how it should remain. Of one thing you can be certain, though, and that is the gratitude of the recipient. Experience shows that the main reward is the abiding inner elation at having given, of your own free will, the greatest possible personal gift to a close fellow human being. Kidney donors deserve considerable credit for their selfless conduct, of which they should always be proud.

What is the task of the Swiss Organ Living-Donor Health Registry?

Anyone with the worthy intention of donating a kidney to another person in need is entitled to discover how those that have already donated a kidney have coped with the situation. This is the specific task of the Swiss Organ Living-Donor Health Registry (SOL-DHR), which provides potential living kidney donors with objective information and meticulously follows up those who have already made a donation. Fortunately, this second edition of the living-donor booklet is able, for the first time, to draw on facts and figures recorded over the past ten years for living kidney donors in all Swiss transplantation centres. For the period from 1 April 1993 to 30 November 2003, the SOL-DHR includes data for 631 living kidney donors. SOL-DHR stands for “**Swiss Organ Living-Donor Health Registry**”. The registry operates under the auspices of Swiss Transplant and the Swiss Nephrology Association. It is the only registry in the world that maintains a constantly updated record of the health of organ donors – and has done so for the past ten years. All living kidney donors are asked to attend a medical check-up one year after donation and every two years thereafter.

Who can answer any other questions I may have?

Your doctor or the specialists in your nearest transplantation centre will be pleased to answer your questions. Alternatively, you can write or e-mail the Swiss Organ Living-Donor Health Registry directly at:

Swiss Organ Living-Donor Health Registry

Universitätsspital Basel, 4031 Basel

E-mail: cnolte@uhbs.ch

Many members of the Swiss Organ Living-Donor Association for Liver and Kidney Donors, all of whom have donated a kidney, are prepared to talk personally with potential future donors and answer any questions on the basis of their own experience.

Contact e-mail for the President of the association, Esther Birbaum:

er.birbaum@bluewin.ch

The association's web site can be found at: www.lebendspende.ch

